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FINAL REPORT

Item No. 3, General

EVALUATION OF **ENCARGUESE DE SU DIABETES: UNA GUIA PARA SU CUIDADO**

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EXECUTIVE SUMMARY

The Division of Diabetes Translation (DDT) of the National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention wrote and produced a preliminary edition of a diabetes patient guide targeted to Hispanic populations entitled **ENCARGUESE DE SU DIABETES: UNA GUIA PARA SU CUIDADO** (Guide). The purpose of the Guide was to provide information to Hispanics with diabetes who use public sector health services on how to take care of and control their disease. After the preliminary edition of the Guide was produced, the DDT sought to evaluate its understandability, relevance, usefulness and adaptability among diverse U.S. Hispanic populations. Under a contract (No. 200-93-0646) with Casals & Associates, Inc. (C&A), the Guide was evaluated through the use of focus group discussions (FGDs). The objectives were to identify the types of health information needed for enhancing the day-to-day management of diabetes and to determine additional appropriate methods for communicating information on diabetes self care.

Throughout the contract period, twenty focus groups were held in five locations (San Diego, California; Miami, Florida; Chicago, Illinois; Houston, Texas; and Toppenish, Washington) among Hispanic populations representing Mexican Americans, Central Americans, South Americans, Cuban Americans, and Puerto Ricans. Local providers associated with state control programs volunteered to serve as site coordinators, and assisted in identifying and selecting focus group participants and sites. The C&A Qualitative Research Specialist was the facilitator for all FGDs. He selected a recorder with background in public health or health-related social science in each location to arrange the FGD room, set up equipment, take informal notes, and prepare and submit a report to C&A. A topic guide was developed as a tool to elicit participant. perspectives about the Guide and additional methods for communicating and disseminating diabetes information. FGDs were held in two phases: the first phase was to evaluate the preliminary Guide produced by CDC; the second phase evaluated the revised Guide based on the suggested and approved changes and additions made by participants in the first phase, and concentrated on eliciting perspectives on additional methods for communicating information on diabetes self-care. Results of Phase I FGDs were related to enhancing the clarity, and amplifying or adding information to the contents of the Guide. Results of Phase II FGDs resulted in few changes to the revised Guide, and useful suggestions for communications approaches and information dissemination.

A video concept paper and video script were developed based on information obtained during FGDs. The script presents a story of an Hispanic family whose main characters initially experience fear and denial of diabetes, but slowly evolve into the more hopeful stages of control and prevention. To ensure technical and cultural accuracy, C&A had the script reviewed, without cost to the project, by an Hispanic physician and an Hispanic behavioral scientist from the public health arena.

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1. STATEMENT OF THE PROBLEM

The Division of Diabetes Translation (DDT) of the National Center for **Chronic Disease** Prevention and Health Promotion, Centers for Disease Control and Prevention wrote and produced a preliminary edition of a diabetes patient guide targeted to Hispanic populations entitled **ENCARGUESE DE SU DIABETES: UNA GUIA PARA SU CUIDADO** (hereinafter called the Guide). The purpose of the Guide was to provide information to Hispanics with diabetes on how to take care of and control their disease. The production and distribution of this Guide will play an important role in providing knowledge and information to disproportionately-affected Hispanic populations on diabetes complications and self-care management.

2. EVALUATIVE OBJECTIVES

2.1 Overview

After the preliminary edition of the Guide was produced, DDT released a request for solicitation (No. 200-93-0646(P)) seeking a contractor to evaluate the Guide. The results of the evaluation would lead to the production of a culturally-relevant Guide that would be as readable as possible for those with at least a sixth grade level of education. The Guide was to provide information on diabetes complications and self-care management. In addition, the contract called for the submission of a video concept paper and a Spanish language script that could be used in producing a video (under a separate contract at a later time) that could accompany the Guide. Casals & Associates, Inc. (C&A) was awarded the contract, which began in October 1993.

2.2 Purpose and Objectives of the Evaluation

The purpose of the evaluation was to determine the understandability, relevance, usefulness and adaptability of the Guide among diverse U.S. Hispanic populations through the use of focus group discussions (FGDs). The objectives were to identify the types of health information needed that would enhance the day-to-day management of diabetes and to determine appropriate methods for communicating information on diabetes self care. Information gained from the evaluation was to form the basis for making revisions to the Guide, as well as for the development of the video concept paper and the Spanish language script.

3. METHODOLOGY

3.1 Overview

The evaluation was conducted in two phases (Phase I and Phase II) through the use of FGDs. Phase I took place in February and March 1994; Phase II in August 1994. FGDs were held in five state locations. The CDC-approved states and locations were California (San Diego); Florida (Miami); Illinois (Chicago); Texas (Houston) and Washington (Toppenish). The Phase I evaluation produced a revised Spanish version of the Guide, which was tested 'in Phase II FGDs for subsequent finalization, production, and distribution. Attachment A shows a breakdown by state and location, site, date, number of participants, Hispanic populations representation, and gender distribution for both phases.

During the project start-up meeting in early November 1993 at the DDT offices in Atlanta, the Co-Project Officers arranged a teleconference call among the five diabetes state control program (DCP) offices and the C&A Project Director and Qualitative Research Specialist for the purpose of making introductions and discussing the methodology and process for conducting the evaluation. Providers associated with the respective state diabetes control programs volunteered to serve as site coordinators. They rendered assistance with the identification and selection of focus group participants and sites, as well as the logistics of the FGDs. Throughout the entire period of this study, C&A found their assistance to be timely and valuable. Their willingness to actively engage in this project played an important role in ensuring the smooth implementation of a study that required considerable logistical management. In addition, the support received from the Co-Project Officers was also timely and provided the technical direction that was needed, especially after the completion of the Phase I FGDs, where the results showed a need to make significant revisions and additions to the Guide.

3.2 Evaluation Procedures

This section describes the procedures followed for both Phase I and Phase II of the evaluation study.

3.2.1 Process for Conducting the Evaluation

A. Contact with State Diabetes Control Programs: Based on the conversations that took place in the November 1993 project start-up meeting, C&A contacted the site coordinators by telephone and through letter regarding the purpose of the evaluation; the criteria for site and participant selection; and the proposed dates for conducting the FGDs. At least two weeks prior to the conduct of the FGDs, C&A prepared a packet of

information that was mailed to the site coordinators for distribution to each participant. The packet included the letter of invitation (in Spanish) which described the purpose, format, time, and place of the FGD, and the honorarium, and a copy of the Guide.

B. Methodology and Design: Prior to beginning FGDs in both phases, C&A prepared and submitted to the CDC Co-Project Officers for approval a Methodology and Design document (Deliverables #1 and #6). These documents described the procedures for conducting the FGDs, and the criteria for selecting sites and participants. The following briefly describes the key points:

(1) Criteria for Site Selection:

(a) Community centers or other familiar surroundings.
(b) Ease of transportation to the site for the participants.
(c) FGD scheduling adapted to the wishes of participants.
(d) A room large enough to hold a table of up to ten persons.

(2) Criteria for the Selection of Focus Group Participants:

(a) general ethnic homogeneity, but with variability in place of birth, years of residence in the United States, and levels of acculturation to American society;
(b) non-insulin dependent diabetes with variation in age of onset and a spectrum of diabetes-related complications;
(c) use of public sector health care provider organizations, e.g., community/migrant health centers, city/county public health departments;
(d) approximately equal numbers of males and females;
(e) a broad range of ages (e.g., from mid-30s to elderly); and
(f) a minimum of sixth-grade level of reading ability in Spanish.

(3) Criteria for Recorders: C&A selected individuals from each location to serve as recorders. Criteria included:

(a) university graduate students in public health or health-related social science programs or individuals who had previous experience serving as recorders in similar FGDs;
(b) persons fluent in English and Spanish; and
(c) to the extent possible, individuals from the same Hispanic populations represented in the FGDs;

Through telephone conversation and letter, the role and responsibility of the recorder was clearly defined for the selected recorders before each phase was underway. Responsibilities included setting up the table for discussion; operation of the tape recorder during FGDs; taking notes on salient points of discussion; and preparation of a report which included correlation of the audio tapes with the recorder's handwritten notes. Recorders were paid for their services, which were limited to a total of one full day per FGD (one-half, day for recording the FGDs and one-half day for report writing).

3.2.2 Process for Conducting Phase I and Phase II FGDs

A. Topic Guide: A topic guide was developed..and used for both phases of the FGDs. The purpose of the topic guide was to serve as a tool to elicit participant perspectives on the Guide's relative ease of comprehension, practicality, and usefulness. Additional questions were included to solicit suggestions for specific and general changes on the layout and drawings in the Guide, as well as changes in the subject matter itself. Finally, questions were asked to solicit suggestions for alternate effective methods and media for communicating diabetes information.

B. Discussion Format: Each FGD was to consist of no more than nine participants, to be conducted in Spanish, and to last a maximum of one and one-half hours. Before each FGD began, participants and any family members who may have accompanied them to the site gathered for an informal reception. During this period, the site coordinator and, if possible, a DCP representative introduced the participants to the facilitator and recorder. Before the beginning of each FGD, the site coordinator, the DCP representative, and any accompanying family members left the room.

C&A's Qualitative Research Specialist served as facilitator for the FGDs. FGDs were held around a table; name cards were placed on the table in front of each participant and the facilitator. The recorder set up the tape recording equipment, which had a multidirectional microphone centered on the table, but sat away from the group. The facilitator opened discussions by thanking participants for agreeing to take part; explaining the purpose and format of the FGD; and assuring participants of confidentiality. Participants were encouraged to be open and frank in their remarks and suggestions. At the conclusion of each FGD, the facilitator collected any marked copies of the Guide, the participants brought with them to the session and provided the participants with new ones. The site coordinator, state DCP representative, and accompanying family members were invited to re-enter the room where there was an open question-and-answer session to respond to diabetes-specific questions that arose during the FGD. At the conclusion of this session; the participants collected their honoraria and departed. The facilitator and recorder then provided the site coordinator and DCP representative with a briefing on the process and outcome of the FGD.

C. Analysis Reports

C&A prepared and submitted to the Co-Project Officers an analysis report for each phase of the FGDs (Delivery Schedule Item No. 9 and No. 18). The reports gave information on the participants' places of birth, gender, and age, described the procedures followed and provided a detailed discussion on recommendations made by the FGD participants on the proposed revisions to be made in the Guide. In compiling the analysis reports, C&A reviewed the recorder reports and reviewed the audiotapes.

3.2.3 Process for Making Revisions to the Guide

Based on the recommendations made and approved by CDC in the Analysis Reports, C&A incorporated the additions and revisions to the Guide. The most extensive changes occurred in Phase I where completely new sections were added and the layout was revised in order to provide an easier method for following and identifying content information within the text. In addition to the approved recommendations, CDC added a section on the Diabetes Complications and Control Trial. Additions and revisions entailed translation into Spanish, insertion into the Spanish language Guide, and making the corresponding changes in an English version of the Guide, noting all changes through the redlining and strikeout method (Deliverable Nos. 3 and 8).

Once the Phase I revisions were completed, C&A conducted a readability test on the revised Guide, using the two readability tests (Crawford and SMOG) approved by CDC. The Crawford method has been used in the education sector to test Spanish language materials. It adjusts for the high number of syllables that comprise many commonly-used words in the Spanish language. SMOG is frequently used to test health and patient education materials, but has not been adapted for Spanish language testing. As anticipated, the results between the tests showed differences in grade level. The Crawford method resulted in a grade level of 5.5; SMOG, a grade level of 9. Phase II readability testing was eliminated since the Phase II revisions to the Guide 'were minimal and would not have resulted in any changes in reading levels.

3.2.4 Process for Developing the Video Script

Perspectives and suggestions elicited in the FGDs provided the basis for preparing a video concept paper, which was the foundation for developing the Spanish language script (Deliverable #10). With the completion of Phase I FGDs, C&A prepared and submitted a preliminary media concept paper based on the recommendations made by participants regarding their views on diabetes educational materials and the methods for presentation. Three points were consistent among all the groups: (1) emphasize prevention and control in order to provide hope and confidence; (2) gear presentations toward the family rather than the individual; and (3) present materials in Spanish and

English. There were, however, significant differences among participant suggestions regarding the type of media for presenting educational materials. For example, Mexican American groups expressed enthusiasm for personal testimonial, story-oriented videos while Cuban American groups expressed no interest in videos, but rather in professional presentations and written materials. In order to clarify educational needs and presentation style, the latter portion of Phase II FGDs was specifically focused on content and media type. Results of Phase II FGDs showed that:

- a video would be the best medium for reaching low-literate audiences;
- the presentation should take the form of a story, within a family context, focusing on a three-generational, extended Hispanic family environment;
- health messages should be delivered by family members based on their experience, although health professionals should present information to lend legitimacy; and
- the story should take place in several culturally-appropriate settings in which a variety of activities are taking place.

In addition, while participants stated video would be the best medium for presenting education materials, they also suggested brochures and other print materials should be developed in Spanish that would give information on locations and telephone numbers of local sources for diabetes health services.

Based on these findings, C&A developed a Spanish language video script within a family context in which the main characters initially express common reactions to diabetes of denial and fear, eventually developing to the more hopeful state of control and prevention. The story evolves in several stages: non-control, sickness, death; misconceptions, counsel and assistance; family encouragement and reinforcement; and control and quality of life. Because the video is intended to serve as ancillary to the Guide itself, C&A has focused on a non-didactic approach emphasizing diabetes control self-care, and health professionals who appear in the video describing how to use the Guide. C&A had the Spanish language Guide reviewed, at no cost to the project, by a barrio community health center-based Hispanic physician for clinical accuracy and by an Hispanic behavioral scientist in the public health arena who lives and works in the Mexican American setting of the video to ensure cultural appropriateness.

4. MAJOR FINDINGS AND RECOMMENDATIONS

4.1 Overview

In both phases of the evaluation, focus group participants were positive in their perceptions of the Guide. Many stated it was the first time they had seen any material written in Spanish that was beneficial to them in caring for the complications of their

diabetes. Although perceptions of the Guide were positive, focus group participants, especially those in Phase I discussions, provided numerous suggestions for improving the understandability, practicality, and usefulness of the Guide.

4.2 Phase I Findings

The majority of FGD participant suggestions for changes (reported to and approved by CDC) were those related to enhancing the clarity and amplifying or adding to the contents of the Guide. These were:

(a) Change the title of the Guide to convey the message that diabetes can be controlled. The title was changed to **CONTROLE SU DIABETES: UNA GUIA PARA SU CUIDADO**;

(b) Present the Guide's opening discussion in a positive, more upbeat manner;

(c) Additions: (1) a clear, concise description of diabetes that will also note the distinction between Type I and Type II diabetes; (2) information on support groups (what they do, how they function), diet (including a list of appropriate Hispanic foods), and physical activity; and a glossary of medical and technical terms;

(d) Amplifications: (1) blood sugar levels, what they mean, how to test, and how to self-administer insulin; (2) alcohol's lowering of blood sugar levels; (3) medications and possible side effects, both physical and emotional; (4) causes (including genetic predisposition, family history, and behavioral factors) and symptoms (physical and emotional) of diabetes; and (5) the chronic nature of diabetes;

(e) Language (Spanish) changes were few and mostly involved the difference in the interpretation of terms between English and Spanish. For example, a change was made from "equipo medico" (medical team) to "profesionales de la salud (health professionals) since the word "team" in Spanish is used in the sense of equipment or a sports team;

4.3 Phase II Findings

The extensive additions and revisions made to the Guide from the Phase I FGDs were well received. Participants expressed satisfaction with the presentation of the Guide; the instructions given; the organization and sequencing of the information; and the use of language, illustrations, and charts. As a result of the effort put into revising the Phase I Guide, few changes were required for the Phase II Guide. Most of the changes

involved nuances of the Spanish language. Two illustrations were found to cause confusion and were therefore deleted.

4.4 Media-related Findings

(a) There is a need for a multimedia approach to diabetes information dissemination. Participants expressed desires to be able to access Spanish language materials in print, audiovisual, and audio forms.

(b) Targeting messages for the diabetes audience should be viewed broadly to include: those diagnosed with diabetes and under treatment; those diagnosed with diabetes, but not under treatment; those with undiagnosed diabetes; and those at risk for diabetes.

(c) Diabetes messages -- regardless of the media form -- should be presented in both English and Spanish to accommodate varying levels of acculturation to American society.

(d) Materials (particularly audiovisual and/or audio) need to be developed that target Hispanic populations who read at less than a sixth grade level of education. Although one criteria in seeking potential FGD participants was that they possess at least a sixth grade level of education, experience showed that in some locations site coordinators could not bring together certain Hispanic subpopulations with diabetes who were using the public sector health services because their level of education was less than sixth grade or they were non-literate.

ATTACHMENT A

Focus Group Breakdown in Phase I and Phase II

Table 1: Phase I (February-March, 1994)

State and Location	Site	Date	No.	Hispanic Subpopulation	Gender Distribution
TEXAS (Houston)					
· Group LA.1	Dehon Center	02/07	6	Mexican Americans	5♀; 1♂
. Group LA.2	Dehon Center	02/08	5	Mexican Americans	3♀; 2♂
CALIFORNIA (San Diego)					
· Group LB.1	Logan Heights Family Ctr	02/10	8	7 Mexican Americans; I Central American	48; 4♂
· Group I.B.2	San Yisdro Clinic	02/10	8	7 Mexican Americans; 1 Central American	58; 3♂
ILLINOIS (Chicago)					
. Group I.C.1	Senior Center, Villa Guadalupe	02/21	8	Mexican Americans	5♀;3♂
. Group I.C.2	Senior Center, Casa Central	02/22	8	Puerto Ricans	6♀;2♂
WASHINGTON (Toppenish)					
. Group I.D.1					
· Group I.D.2	Providence Hospital	02/24	8	Mexican Americans	6♀; 2♂
	Providence Hospital	02/25	2	Mexican Americans	1♀; 1♂
FLORIDA (Miami)					
. Group I.E.1	Hialeah Chamber of Commerce	03/07	4	Cuban Americans	2♀; 2♂
. Group I.E.2	Notre Dame d'Haïti	03/08	3	Puerto Ricans	1♀; 2♂

Table 2: Phase II (August 1994)

State and Location	Site	Date	No.	Hispanic Subpopulation	Gender Distribution
ILLINOIS (Chicago)					
• Group II.A.1	Villa Guadalupe	08/15	7	6 Mexican Americans; 1 Guatamalan	5♀; 2♂
• Group II.A.2	Casa Central	08/15	9	Puerto Rican	7♀; 2♂
WASHINGTON (Toppenish)					
. Group II.B.1	Assembly of God Church	08/17	5	Mexican Americans	4♀; 1♂
. Group II.B.2	Assembly of God Church	08/17	2	Mexican Americans	2♀
TEXAS (Houston)					
. Group II.C.1	Dehon Center	08/22	7	5 Mexican Americans; 2 S. Americans	3♀;4♂
• Group II.C.2	Dehon Center	08/23	4	Puerto Ricans	2♀;2♂
FLORIDA (Miami)					
• Group II.D.1	Hialeah Goodlet Park Adult Center	08/24	4	Cuban Americans	1♀; 3♂
. Group II.D.2	Hostos Adult Center	08/25	2	Puerto Ricans	1♀; 1♂
CALIFORNIA (San Diego)					
• Group II.E.1	San Ysidro Health Clinic	08/29	7	Mexican Americans	3♀; 4♂
• Group II.E.2	Logan Heights Family Health Ctr	08/30	4	3 Mexican Americans; 1 S. American	2♀; 2♂